

Good morning,

I'm sending this email in support of passing bill # HB2563. Krabbe disease should be added to the Newborn screening list.

This Krabbe disease is a devastating terminal disease robbing a child of eyesight, hearing, the muscles needed to eat, sit, walk, everything, until finally taking away the ability to breath and the beat of their heart. A simple blood test is done at birth. The children, who have Krabbe, can have a stem cell transplant and live a normal life.

I have a friend and coworker who's family is trying to keep their son alive and it's a daily struggle, it's life changing for the whole family and their son is just hanging on. He can't see, hear, walk, talk, eat, smile, laugh, just cry when he feels bad or has a fever. This is the most horrible disease I've ever seen and it could be avoided or cured if caught early thru a simple inexpensive test at birth. This family is heartbroken and the strength it's taking all of them to hold on. The in home care alone is in the millions now, since he was diagnosed. They've had to watch him slowly and torturously lose his balance walking, then losing his senses one at a time to a world so dark, silent only the comfort of being held 24/7 in his mother's arms. He's at the level now where I'm praying God brings him home.

Please pass this bill. I'm begging you.

Lili Hegstad

Lili Hegstad / Operations Support Specialist
Providence Health Plans
3601 SW Murray Blvd
Beaverton, OR 97005
503.574.7933
Lili.hegstad@providence.org

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